

The Impact of Dementia on Innovation in Senior Housing in Georgia

MaryLea Boatwright Quinn, LCSW
Director of Government Affairs
Alzheimer's Association, GA Chapter

- Important Data
- Implications
- What other states are doing
- Dementia-capable Medicaid programs

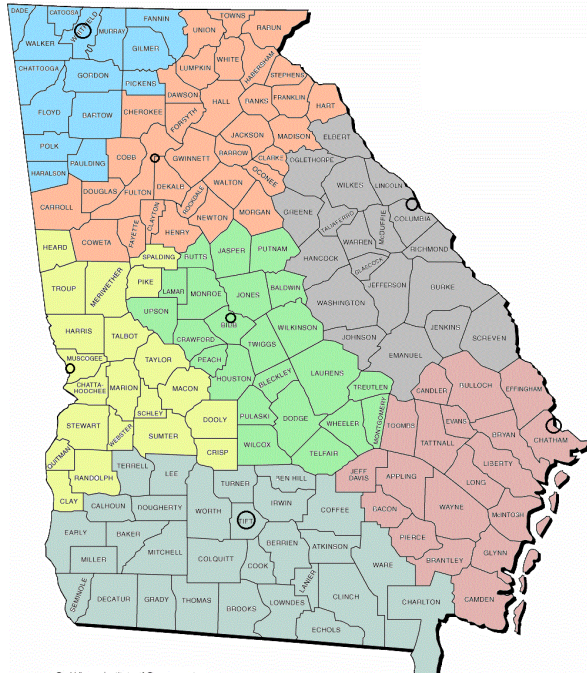
Mission

To eliminate Alzheimer's disease through the advancement of research; to provide and enhance care and support for all affected; and to reduce the risk of dementia through the promotion of brain health.

The Georgia Chapter

The Alzheimer's Association is the leading volunteer health organization in Alzheimer's disease care.

The Georgia chapter has been serving Georgia communities since 1982 by providing local support groups, community education and access to local resources.



Offices in:

- Dalton
- Atlanta
- Augusta
- Savannah
- Macon
- Columbus
- Tifton

alz.org/georgia

The Association is working to get state governments to implement their State Alzheimer's Plans and to:

Increase Public Awareness,
Early Detection and Diagnosis

Build a Dementia-Capable
Workforce

Increase Access to Home
and Community-Based Services

Enhance the Quality
of Care in Residential Settings

To reduce the long-term impact of the disease on state budgets and improve the lives of individuals living with dementia and their family caregivers.

65+ NUMBER OF PEOPLE AGED 65 AND OLDER WITH ALZHEIMER'S BY AGE*

* Totals may not add due to rounding

Year	65-74	75-84	85+	TOTAL
2019	27,000	67,000	53,000	150,000
2025	33,000	90,000	63,000	190,000



MEDICAID

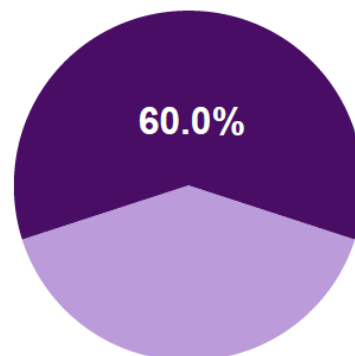
**\$1.180
BILLION**

Medicaid costs of caring for people with Alzheimer's (2019)

↑ 33.5%
change in costs
from 2019 to 2025

Data from the 2017 Behavioral Risk Factor Surveillance System

Percent with memory problems who have not talked to a health care provider



For more information, view the 2019 *Alzheimer's Disease Facts and Figures* report at alz.org/facts.

National Data

5.8 Americans are living with Alzheimer's **MILLION**

BY 2050, this number is projected to rise to nearly **14** **MILLION**

IN 2019, Alzheimer's and other dementias will cost the nation

\$290 BILLION

BY 2050, these costs could rise as high as

\$1.1 TRILLION



 **EVERY 65 SECONDS** someone in the United States develops the disease

Between 2000 and 2017 deaths from heart disease have decreased

9% 

while deaths from Alzheimer's disease have increased

 **145%**



82% of seniors say it's important to have their thinking or memory checked

BUT ONLY

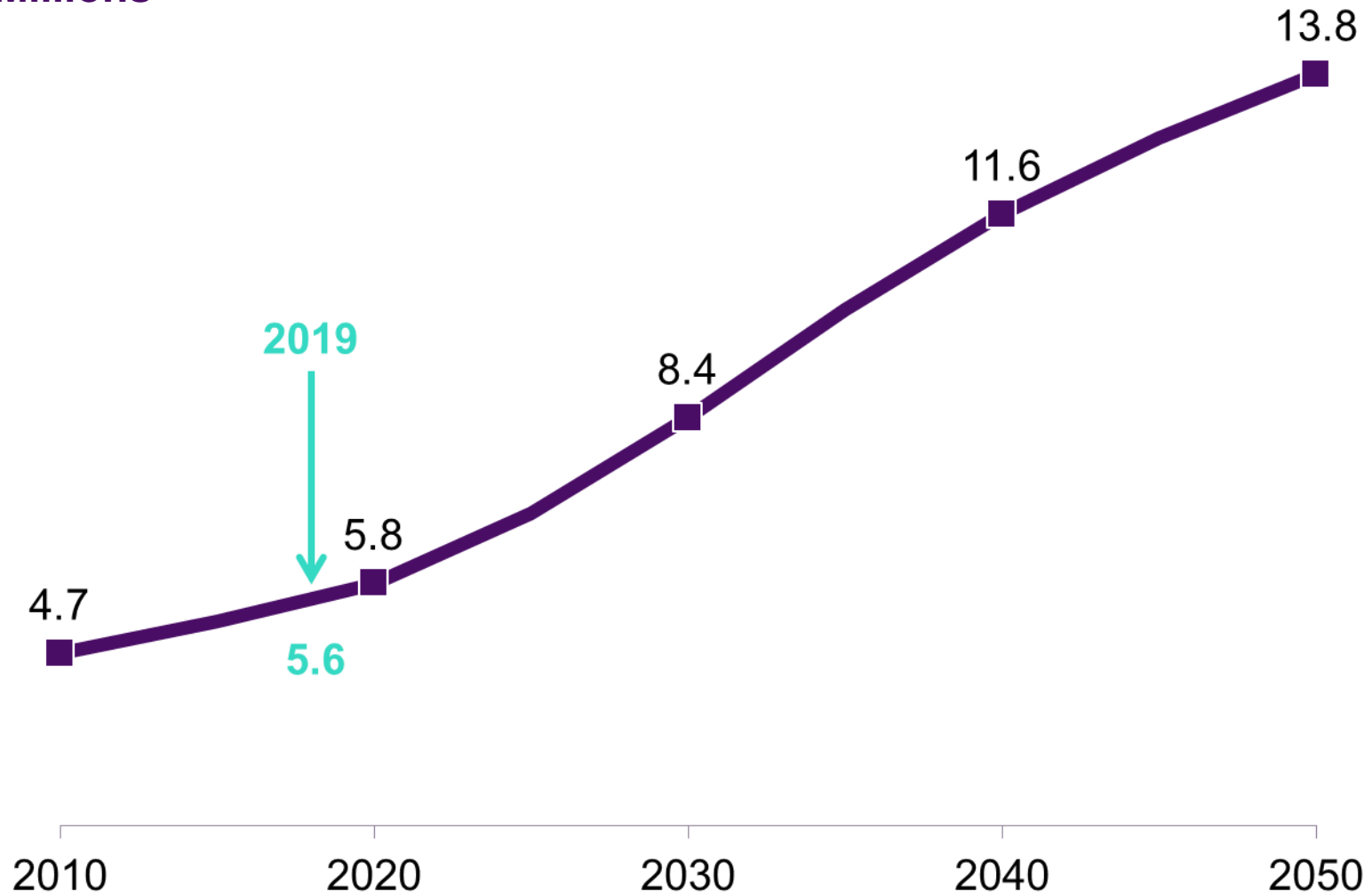
16% say they receive regular cognitive assessments

alzheimer's  association®

THE BRAINS BEHIND SAVING YOURS:

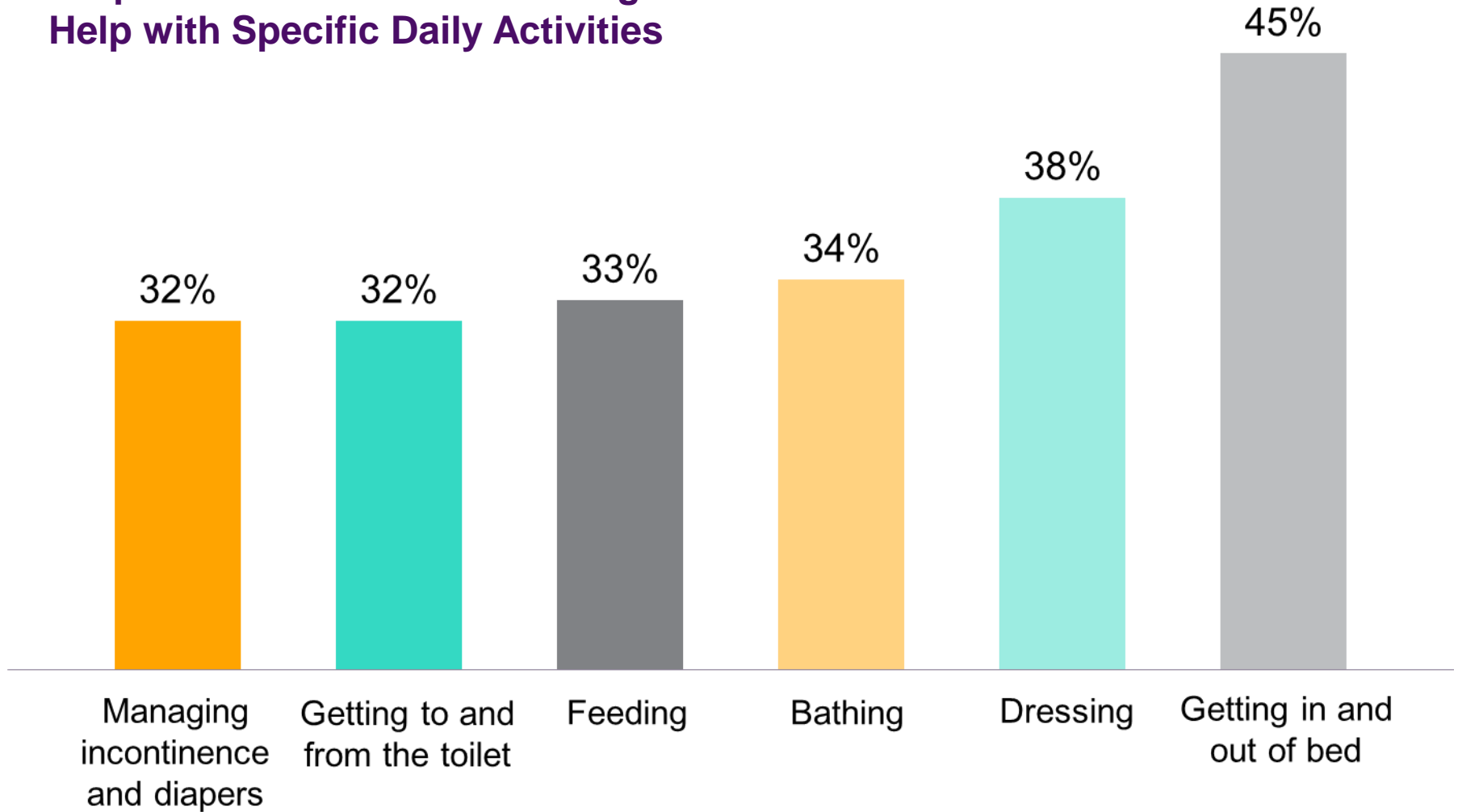
Americans Aged 65 and Over with Alzheimer's

In Millions



Burden of Caregiving

Proportion of Alzheimer's Caregivers Who Provide Help with Specific Daily Activities



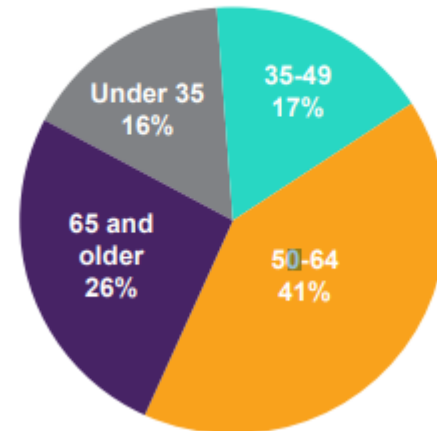
Burden of Caregiving

In 2018, 16.3 million family members and friends provided care for people with Alzheimer's and other dementias.

These caregivers provided an estimated
18.5 BILLION HOURS
valued at nearly
\$234 BILLION

Nearly one-fourth of Alzheimer's and dementia caregivers are “sandwich generation” caregivers— caring for both someone with the disease and a child or grandchild.

Ages of Alzheimer's and Other Dementia Caregivers



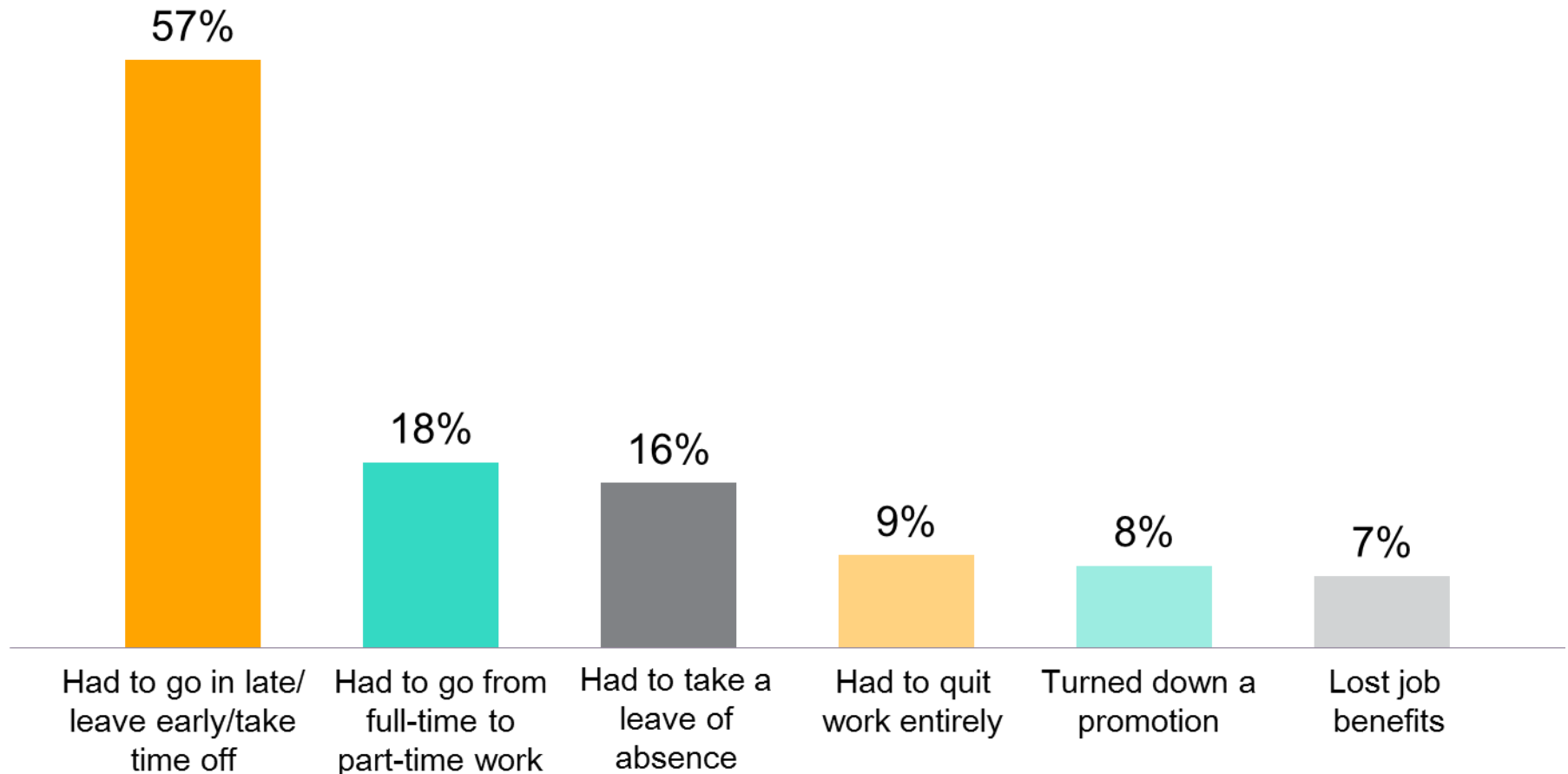
Burden of Caregiving

Caring for an individual with Alzheimer's has a negative effect on employment, income and financial security.

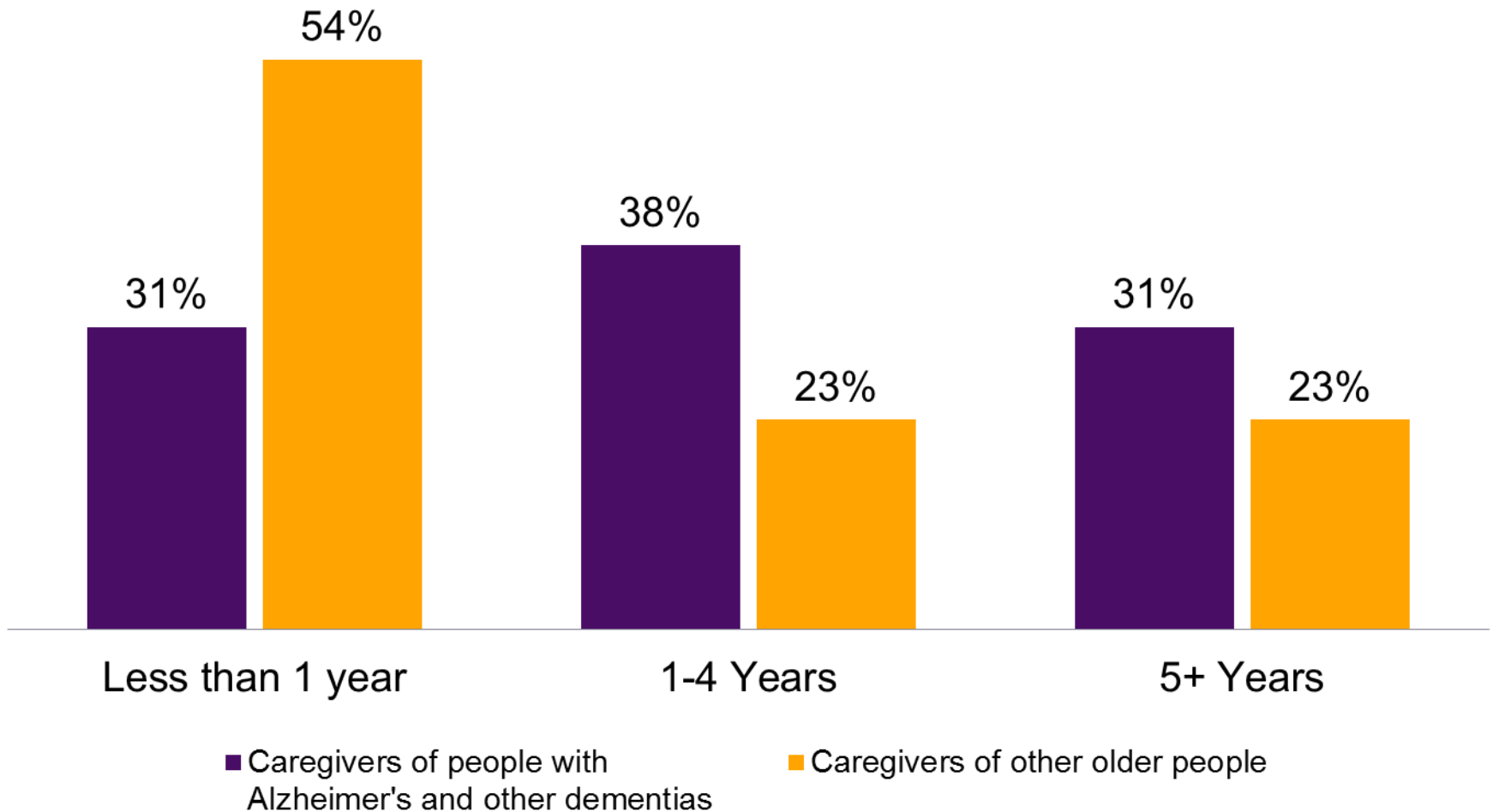
- Among Alzheimer's and dementia caregivers who are employed full or part time, 57 percent said they had to go in late, leave early or take time off because of their caregiving responsibilities.
- In addition, 18 percent had to go from working full time to part time; 16 percent had to take a leave of absence; and 8 percent turned down a promotion due to the burden of caregiving.
- More than 1 in 6 Alzheimer's and dementia caregivers had to quit work entirely either to become a caregiver in the first place or because their caregiving duties became too burdensome.
- Among female caregivers, 17 percent believe they have been penalized at work because of the need to care for someone with Alzheimer's

Work Effects of Caregiving

Work-Related Changes Experienced by Alzheimer's Caregivers

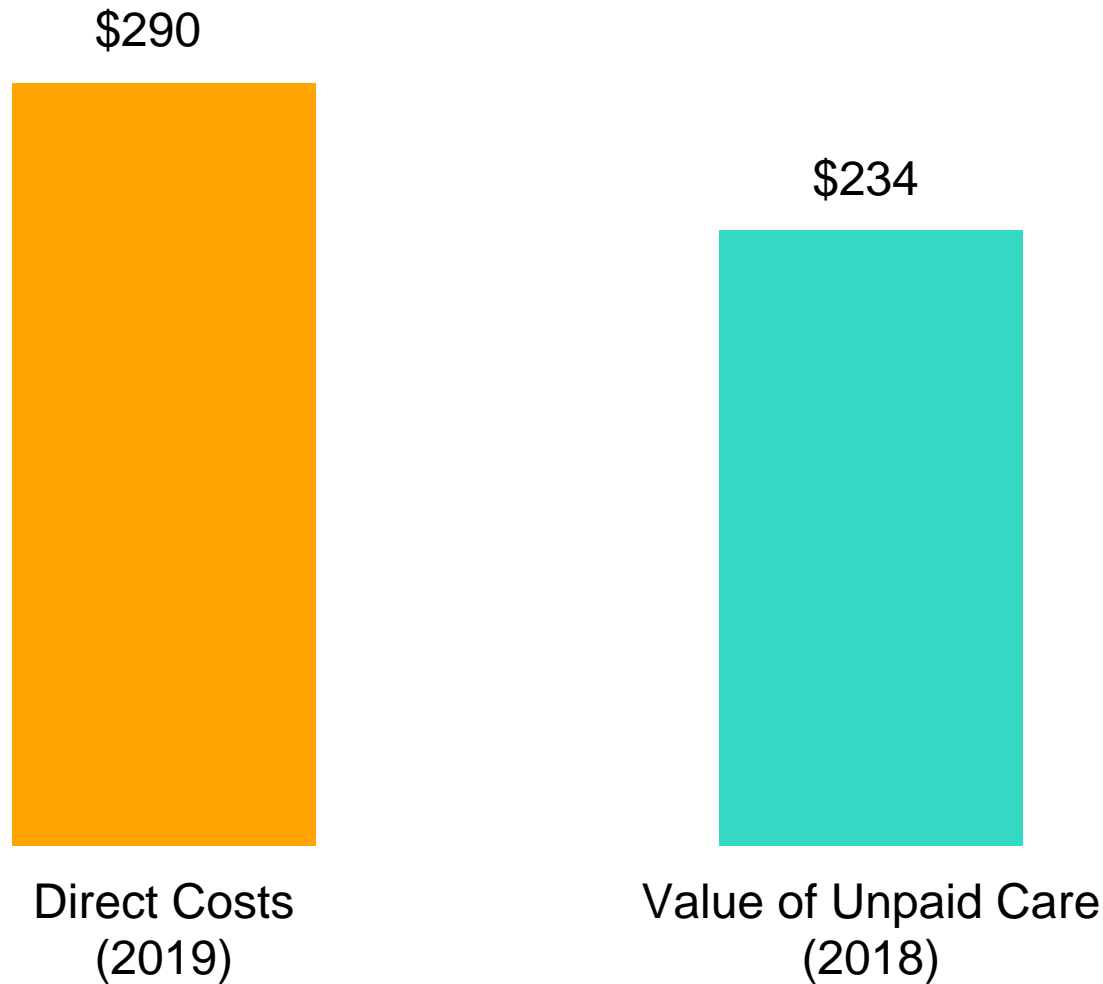


Duration of Caregiving

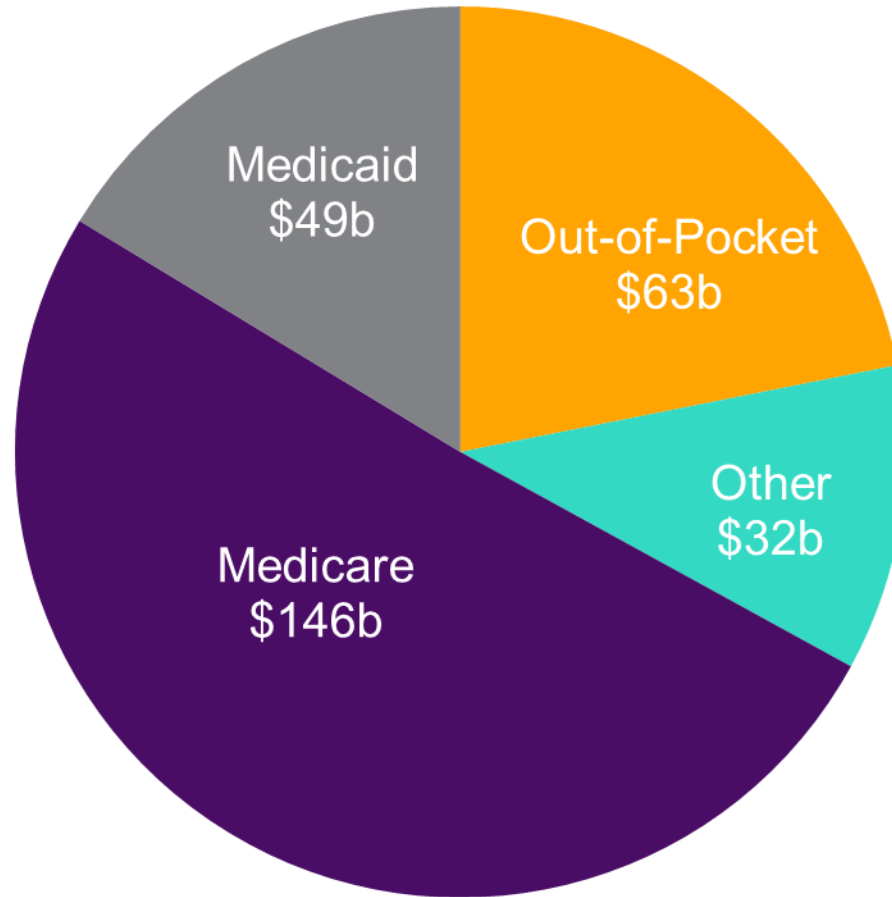


Alzheimer's and Dementia Care Costs

In Billions of Dollars

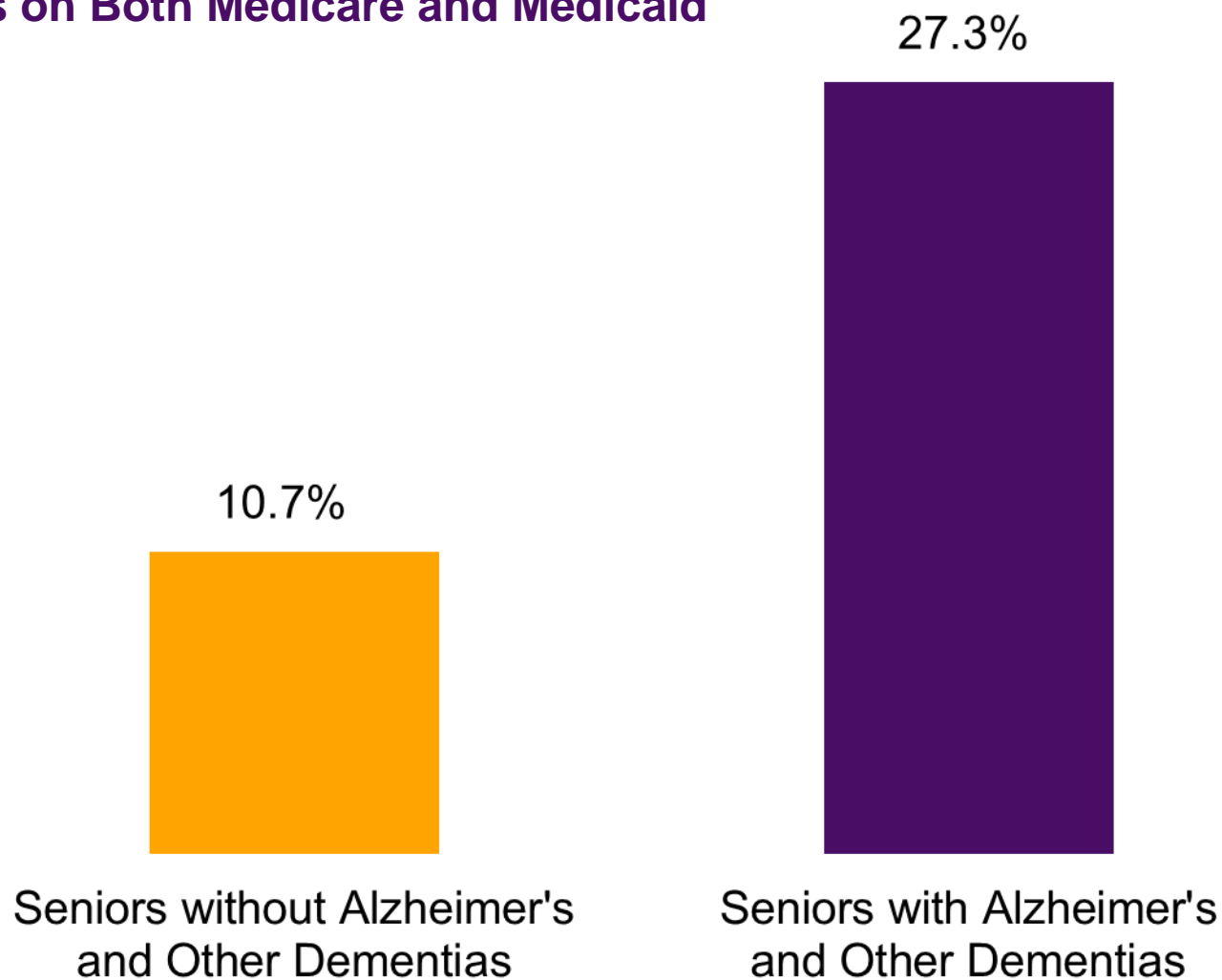


Cost of Alzheimer's Disease, 2019



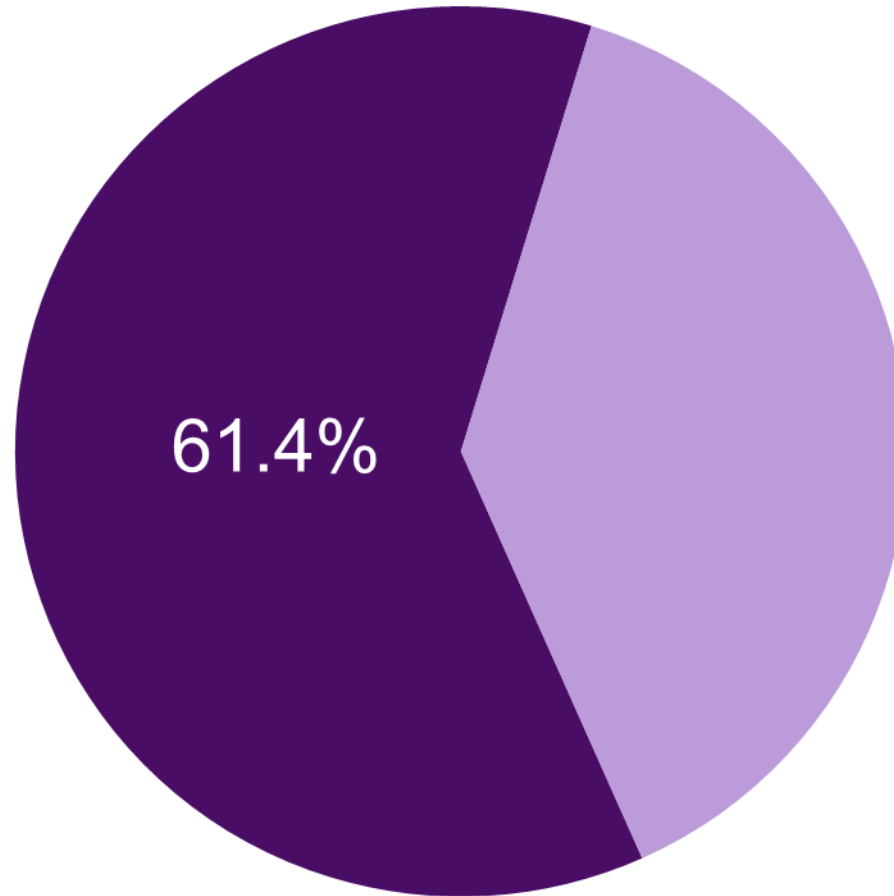
Dual-Eligible Seniors

Seniors on Both Medicare and Medicaid

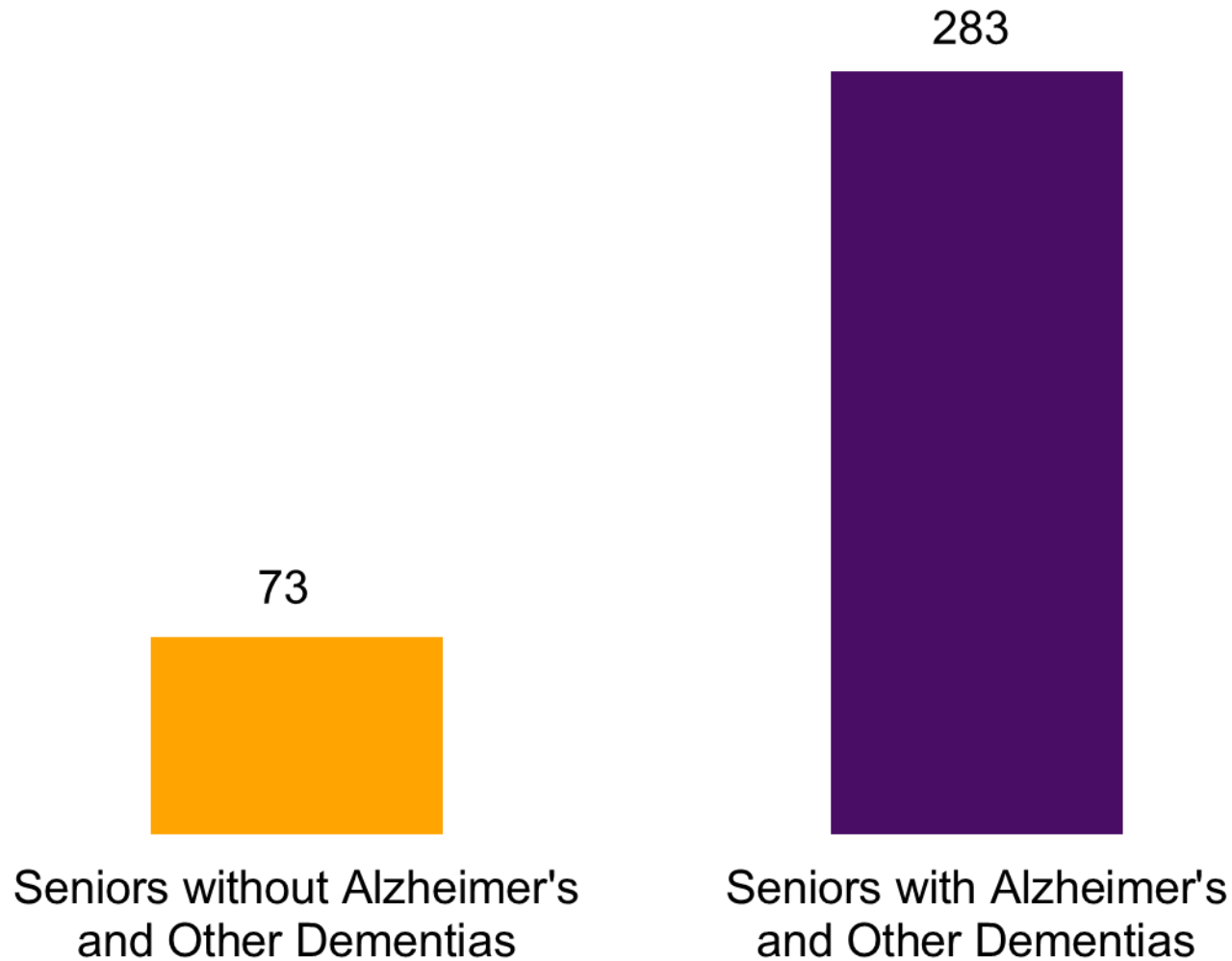


Elderly Nursing Home Residents

Percent with Alzheimer's and Other Dementias



Annual Number of Skilled Nursing Facility Stays Per 1,000 Seniors



Overview of Assisted Living Facilities (ALFs)

- ALFs are community-based residential care settings (RCSs) that offer room, board, and essential care services
- Regulation of ALFs and other RCSs is a state rather than federal responsibility
- All states license at least one category of RCS; the most commonly used licensure category—used by 44 states—is assisted living
- All state Medicaid programs require participating ALFs and other RCSs (ALFs/RCSs) to meet state licensure requirements

Carder et al. (2015). *Compendium of residential care and assisted living regulations and policy: 2015 ed.* Washington, DC: ASPE.

Prevalence of ALFs/RCSs vs. Nursing Homes

- More licensed ALFs/RCSs than nursing homes
 - 28,900 ALFs/RCSs
 - 15,600 nursing homes
- Fewer beds and people served in RCSs than in nursing homes
 - 996,100 beds in ALFs/RCSs; 35 persons per ALF/RCS per day on average
 - 1.6 million in nursing homes; 106 persons per facility per day on average

Harris-Kojetin et al. (2019). Long-term care providers and services users in the United States, 2015–2016. National Center for Health Statistics. *Vital Health Stat* 3(43).

Medicaid in ALFs and other RCSs

- Relatively few ALFs/RCSs are Medicaid-certified
 - 48.3% of RCSs are Medicaid-certified
 - In comparison, 95.2% of nursing homes are Medicaid-certified
- Relatively few RCS residents use Medicaid as their payer source
 - 16.5% of RCS residents used Medicaid as their payer source
 - In comparison, 61.8% in nursing homes used Medicaid as payer source

Greene, A.M., Wiener, J., Khatutsky, G., Johnson, R., O’Keeffe, J. 2013. Medicaid in Residential Care. Washington, DC: ASPE.

Harris-Kojetin et al. (2019). Long-term care providers and services users in the United States, 2015–2016. National Center for Health Statistics. *Vital Health Stat* 3(43).

Dementia special care units in ALFs/RCSs

- Dementia and dementia special care units in ALFs/RCSs
 - 14% of Medicaid-certified RCSs had specialty care compared to 20% of non-Medicaid RCSs
 - Fewer Medicaid-covered residents (35%) had dementia compared to other residents (44%)
 - 20% of Medicaid-covered residents lived in facilities with special care units versus 40% of other residents

Greene, A.M., Wiener, J., Khatutsky, G., Johnson, R., O’Keeffe, J. 2013. Medicaid in Residential Care. Washington, DC: ASPE.

Harris-Kojetin et al. (2019). Long-term care providers and services users in the United States, 2015–2016. National Center for Health Statistics. *Vital Health Stat* 3(43).

Medicaid Financing of Assisted Living Services

Medicaid Authorities

- State Plan Personal Care Option
- §1915 (c) HCBS waivers
- §1115 waivers
- §1915 (i) State Plan Option
- §1915 (k) Community First Choice
- §1915 (b) Managed Care Waivers

Provisions Impacting Access

- Program eligibility requirements (e.g., institutional level-of-care criteria)
- Financial eligibility requirements (e.g., states may set a higher income standard for eligibility)
- Access to services (e.g., can target services to specific beneficiary groups, but cannot cap enrollment or limit to certain geographic areas)
- Other criteria (e.g., must demonstrate innovative financing or service delivery system)

Lepore et al. (2017). Medicaid beneficiaries' access to residential care settings. *Journal of Housing for the Elderly*, 31(4), 351-366.

State Examples: Medicaid Authorities

Utilizing Medicaid to supplement or pay for room and board in ALFs

State	Funding Authority
Colorado	§1915(c) HCBS waiver
Florida	§1915(b)/(c) waiver
	State Plan Personal Care
North Carolina	State Plan Personal Care
Washington	§1915(k) Community First Choice Program

Lepore et al. (2017). Medicaid beneficiaries' access to residential care settings. *Journal of Housing for the Elderly*, 31(4), 351-366.

North Carolina

- SSI Beneficiaries can qualify for a benefit called Special Assistance (SA) that will pay for room and board expenses, up to \$1,182/month, at adult care homes (also known as assisted living facilities). People with dementia who live in specialized care units can receive more money each month (\$1,515). +\$46 Personal allowance
- Those not on SSI, income must be lower than \$1,229 per month (in 2018) and must have less than \$2,000 in countable assets (excluding your car, home, and personal effects). Those seeking to live in special care units (like memory care) must have income less than \$1,561 per month.

Funding Authority:
State Plan Personal
Care

<https://www.ncdhhs.gov/assistance/adult-services/state-county-special-assistance>

Florida

- In Florida assistance with room and board is available in assisted living facility (ALF) and adult family care home (AFCH). AFCHs have no more than five residents, and the operator of the home must live in the home.
- ALFs and AFCHs can be covered by Florida's LTCMC plans. Each LTCMC plan will contract with its own providers, so not every ALF or AFCH will be covered under every plan.
- Florida also has a non-Medicaid program called Optional State Supplementation (OSS) that helps low-income qualified individuals pay for room and board at ALFs and AFCHs.

Funding Authority:
§1915(b)/(c) waiver
State Plan Personal
Care

*Florida's Medicaid
Long-Term Care
Managed Care
(LTCMC)

Illinois

- New program authorized in August 2019 that will serve 1600 Medicaid members that have dementia
- They are part of the Supportive Living Program (SLP), an HFS Medicaid alternative to nursing home care designed for older persons and persons with physical disabilities.
- SLP residents have their own apartment, decide which program services they will receive and determine their own schedule. Services include meals, housekeeping, laundry, medication management, assistance with activities of daily living, social and health promotion activities, emergency call systems, wellbeing checks and routine nursing assessments.
- Residents in a dementia care setting receive increased oversight by staff and additional nursing assessments and are provided opportunities for more activities, all in a community setting.
- The Supportive Living Program began in 1996 and currently has 152 providers with over 12,700 apartments. Five sites are currently certified as dementia care settings.
- SLP operates through a Home and Community Based Services waiver approved by federal CMS. This allows Medicaid funds to pay for assisted living services for eligible Medicaid participants who might otherwise live in a nursing home.

Supportive Living Program

Funding Authority: HCBS Waiver

<https://www.illinois.gov/hfs/MedicalPrograms/slf/Pages/default.aspx>

<https://www2.illinois.gov/Pages/news-item.aspx?ReleaseID=20553>

Considerations

- **Functional eligibility assessments** measure the need for assistance with activities of daily living (ADLs), which include bathing and dressing, and instrumental activities of daily living (IADLs), such as shopping and cooking.
- **Functional assessments for LTSS eligibility may not fully capture the needs and limitations of people with dementia.** During assessments, cognitive impairments are often not weighted as strongly as physical impairments even if they produce virtually the same level of functional difficulty. Functional assessment tools that only focus on the physical capabilities associated with ADLs and IADLs could potentially exclude people with dementia.

Recommendation

- **Ensure that individuals with dementia are able to access needed Medicaid long-term services and supports-**
functional eligibility criteria should include and properly weight issues related to cognitive impairment, particularly in regard to prompting, monitoring and supervision of daily activities & consistent training of those who conduct the Medicaid functional assessment
- state eligibility criteria often do not explicitly address issues related to supervision and monitoring of behavioral symptoms related to decision-making resulting from impaired judgment. To ensure that individuals with dementia are able to access needed Medicaid long-term services and supports, functional eligibility criteria should include and properly weight issues related to cognitive impairment, particularly in regard to prompting, monitoring and supervision of daily activities.

Recommendation

Medicaid Waiver programs need to be more dementia capable to meet the growing population with these needs. New programs and existing programs need to make necessary changes to ensure the needs of this population are met and thereby decreasing costs and improving quality of care.

Examples include:

- Personal Emergency Response Systems (PERS) being a Gyroscope-based fall detection rather than requiring a user to push a button
- Medicaid programs for personal assistance tend to focus care on ADLs and IDLs in providing Personal Care Services vs Companion Care services which could be sufficient for oversight and supervision in early to moderate stage dementia
- Ensuring that all who administer the Functional Eligibility testing criteria are consistent and adequately trained in dementia

Acknowledgements

- Molly Knowles, Kristie A. Porter, Janet O’Keeffe, Joshua Wiener
- Lepore, M., Knowles, M., Porter, K. A., O’Keeffe, J., & Wiener, J. (2017). Medicaid beneficiaries’ access to residential care settings. *Journal of Housing for the Elderly*, 31(4), 351-366.

Comments/Questions

alz.org/georgia

mboatwrightquinn@alz.org

404-728-6048

MaryLea Boatwright Quinn, LCSW
Director of Government Affairs